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Parents' Experiences of Administering Distressing Nursing and Healthcare Procedures as part of Supporting Children with Complex or Long-Term Conditions at Home

Final Report

Working Paper WC 2671 - June 2016

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Contributions of Authors

Gemma Spiers co-developed the original proposal, managed the project throughout, developed the research materials, undertook data collection and analysis and led on writing the final report.

Bryony Beresford co-developed the original proposal, supervised Gemma Spiers, developed the research materials, contributed to data analysis and contributed to the final report.

Susan Clarke undertook data collection.

Executive Summary

Background

Parents of children with long-term and complex health conditions often assume responsibility for aspects of their child's ongoing nursing care at home. Sometimes, this involves procedures that cause distress for the child. Very little is understood about parents' experiences of this, including if and how they think it affects them, their child and their family, and how best they would like to be supported. This is an important issue to understand given the increasing move to deliver children's healthcare in the community and more nursing responsibility shifts to parents. This study was funded to explore these issues, guided by three research questions:

- What are parents' experiences of administering procedures that cause their child distress as part of caring for them at home?
- When parents are responsible for administering these procedures, what is the perceived impact of this on the parent-child relationship, parental and child wellbeing, and the family?
- What are the support needs of parents with this responsibility, both at the point of being trained and prepared to undertake such procedures, and in the longer-term?

Methods

An exploratory study, using in-depth interviews with parents, was used. We purposively sampled and interviewed 19 parents who were responsible for carrying out procedures they believed caused distress for their child. In five cases, we also interviewed their partners/spouses. Procedures represented in the study sample included: inserting naso-gastric tubes, inserting gastrostomy tubes, changing tracheostomy tubes, giving injections, finger/thumb pricks, oral suctioning, nasal suctioning/prongs/other nasopharyngeal procedures, changing dressings, administering suppositories, colostomy care and bladder manipulation. A thematic analysis of the interview data was used to understand parents' experiences of carrying out these procedures.

Findings

Parents became responsible for taking on these procedures in a range of circumstances. Some proactively chose to assume this responsibility. Others took on the procedures as a condition for going home from hospital with their child, and some took them on with reluctance because there was no one else to carry them out. Where parents proactively chose to take on these procedures, they made trade-offs between the emotional discomfort they felt in causing their child distress, and the wider benefits it would bring to the child or family (e.g. being able to stay at home).

The procedures themselves were a technical process, which parents had to carefully orchestrate (e.g. preparing equipment). However, it was not just the technical delivery of the procedures that parents managed. The nature of the procedures (ie. that they caused distress for the child) meant there were additional issues and challenges that parents had to contend with. These included managing their child's distress and resistance (physical and/or verbal), their own emotional response, and the reactions of siblings present in the home. There were also concerns about the implications of incorrectly administering the procedures (e.g. misplacement of nasogastric tubes) in terms of their child's health.

Efforts to prevent and/or minimise the distress their child experienced was a core part of parents' experiences, with a range of techniques developed, tried and used. Sometimes this was guided with the help of professionals, but in most cases, parents were directing their own efforts in this. Where they felt less confident managing their child's distress, there was a need for professional advice, though not all received this.

The second of our research questions concerned if and how carrying out these procedures affected parents, their family, and their relationship with their child. We found that in most cases, carrying out the procedures was, to vary degrees, an emotional experience for parents. However, this did not appear to translate into an ongoing emotional burden for most, with the majority expressing either a sense of acceptance for their responsibility, or a view that it had become easier over time. Where the emotional burden was more prominent and ongoing, this was situated in experiences of poor professional support, struggles to manage their child's distress, concerns about how their child viewed them and/or a perceived absence of choice in being responsible for the procedures.

Most felt that their relationship with their child was unaffected by their involvement in the procedures, with any conflict being time limited to the point at which the procedure was carried out. However, for a minority there were concerns about how their child viewed them, including worries about being viewed as "the bad parent".

Experiences of training in carrying out the procedures and ongoing support from healthcare professionals varied among those we spoke to. Training received ranged from extensive and thorough to minimal and rushed. Sometimes it included advice about managing distress and resistance. Others reported that this and parents' emotional discomfort were given little consideration. Similarly, once at home, ongoing training and support ranged from being "left to get on with it", with no monitoring or input from health staff, to having a network of support from ward and community nurses.

Important ways of being supported identified by parents included:

- Advice about managing the child's distress and resistance;
- Psychosocial support from nurses and peer (i.e. other parents) support for the emotional aspects of the role;

- Assistance with the procedures (e.g. managing resistance);
- Recognition from health professionals of the responsibility that has been assumed;
- Occasional supervision and observation from nurses to feel reassured and informed about the procedures.

Implications

This study has, for the first time, explored and described parents' experiences of being responsible for administering distressing procedures to their child. It has revealed that, at least in the early days, parents may have to learn to manage a number of issues beyond the technical delivery of the procedure including the child's distress and resistance, parents' own emotional response, and the presence and reactions of siblings. Importantly, these issues may not always be visible or obvious to health staff once parents take on the procedures at home. This has implications in the way parents are trained and supported in this role.

The study has highlighted the emotional, practical and informational support which parents require. Addressing some of these needs may have resource implications (such as increased provision of outreach/children's community nursing teams). Other needs, such as improving training and greater recognition of the impact on parents could be incorporated into existing practice. Furthermore, whilst some support needs are clearly the domain of nurses or other healthcare professionals, it is important to also note that parents highlighted the value of, or called for opportunities for, peer support.

Study definitions and terminology in the report

The procedures represented in this study

In conceiving and developing our ideas for this study, our focus of interest was procedures that *parents* carried out and which *they* thought caused their child some sort of distress because they were experienced as painful or invasive. Thus, given the subjective nature of any experience, we were not prescriptive about which procedures could be represented in this study.

Our working definition of ‘invasive’ referred to procedures which involved the introduction of instruments or other objects into the body or body cavities. However, we found that the term ‘invasive’ was conceptually ambiguous. In accounting for the distress caused by a procedure, parents did not make explicit reference to its invasive nature in terms of offering an explanation for why it caused the child distress. Rather, they perceived the distress as being the result of physical discomfort and/or the requirement for the child to be still or held in a particular position whilst the procedure was executed.

Thus for the sake of accuracy and consistency in the report, we use the phrase ‘procedures that caused [the child] distress’. For clarity, we further define our terminology below.

Distress

We defined this as a response indicating that their child disliked what was happening to them during the procedure. This was inferred by parents from the child’s verbal and/or physical responses. In most cases, this distress was thought to arise because the procedure was, in parents’ views, being experienced as painful or physically uncomfortable. More detail is given on pages 24 and 25 for each procedure, but examples of these verbal and physical cues could include the child crying, saying the word ‘no’, rolling away or banging their head.

It is important to note two caveats in our use of the word distress. First, as parents’ experiences revealed, some observed that their child’s distress responses changed over time, and so the experience of distress is not static. Second, whilst parents’ accounts suggest their child found the procedure distressing because it was painful or physically uncomfortable, there was also evidence in a minority of cases that such distress could be caused by the fact that the procedure had interrupted, or prevented the child in taking part in, a more pleasurable activity. Thus, distress may not always have been the result of the procedure being painful or physical uncomfortable.

Painful

A physical sensation causing distress, and more extreme than 'physically uncomfortable'.

Physically uncomfortable

This refers to a physical sensation that causes distress, but which is not as extreme as pain. Many parents made the distinction between procedures that produced pain and those that were physically uncomfortable.

Emotional discomfort

This refers to parents' emotional response to carrying out the procedures. It encapsulates a feeling that parents were not at ease with the procedures because of the distress caused to their child. Page 29 offers the descriptions that parents used to illustrate how they found carrying out the procedures, all of which imply some degree of emotional discomfort.

Resistance

This refers to the child's verbal resistance in anticipation of, and to avoid or delay, the procedures, and physical resistance during the procedure. Verbal resistance was protestations. Physical resistance could include, for example, struggling or moving away, which we infer to be a way for the child to prevent something they did not like, whether this was because the procedure was painful or physically uncomfortable, or because of another reason (e.g. that they wanted to be doing something else). Restraint was used to prevent physical resistance, and restraint itself was seen by some parents as a cause of the child's distress.

CHAPTER 1: BACKGROUND

Parents of children with long-term and complex health conditions often assume responsibility for parts of their child's ongoing nursing care. Sometimes, this involves nursing tasks, for example, passing naso-gastric tubes [e.g. 1, 2]; anal dilation following surgery [e.g. 3, 4]; tracheotomy care [e.g. 5]; managing infusion pumps for children with sickle cell disorder [e.g. 6]; and other unspecified technical care [e.g. 7]. There are some studies showing that parents find this responsibility difficult because of the distress caused to the child [1, 3, 8], and may decline it altogether [9, 10]. Being responsible for procedures that cause distress for the child can compromise parents' identity [1]. Even where parents are not directly responsible for carrying out such procedures, the act of restraining a child whilst hospital staff carry out such procedures can be difficult to reconcile with the parenting role and may result in feelings of guilt [11, 12].

Although these studies highlight that parents carry out procedures that they themselves can find difficult (because they cause distress for the child), this evidence typically arises from studies examining the wider issues relating to parental caring for ill children. Therefore, they only provide a small and limited picture of the implications of this situation. Others have speculated there may be consequences for the parent-child relationship and wellbeing [3, 11], but no research has examined this. Similarly, there is no research about the impact on the wider family (e.g. siblings) and the possible impact on the relationship between parents themselves has only recently been raised as an issue in relation to transanal irrigation [8]. Ultimately, this is an under-researched area and our understanding of these issues is limited.

In comparison, the implications for health-care staff of carrying out procedures that cause the child distress have been given more consideration, and particularly in hospital settings. For example, current UK guidance about managing procedures that may cause a child distress are geared towards healthcare staff rather than parents [13, 14]. For staff in hospital settings, there is evidence that carrying out such procedures can be a source of emotional stress. Here, support from other ward staff and supervisors plays a role in alleviating its impact [15]. Not only does this raise questions about how parents manage the emotional impact associated with being responsible for administering these procedures, but also how they do so in the home, which is likely to be a much more isolated setting compared to a nurse on a ward.

There is, however, a reasonable body of evidence about the *passive* involvement of parents when healthcare practitioners undertake these procedures in hospital settings (e.g. distracting the child during the procedure). This research typically focuses on assessing parents and children's emotional and behavioural responses and coping strategies [16-24], and the effectiveness of interventions to manage the child's distress [25-28]. However,

there is no equivalent research examining behaviours, coping and management of distress when parents are directly responsible for these procedures at home, even though this is a known part of their caring role.

There is, in essence, a clear gap in terms of what is known about parents carrying out procedures that cause distress for their child when done so at home. This is surprising, as such knowledge is salient to the way care for children with long-term and complex needs is increasingly delivered. Both the national policy push to deliver more care closer to home [29, 30] and the growing numbers of children with life limiting conditions [31] means it is likely that more parents will assume responsibility for their child's nursing care, and do so in the home setting. Parts of this care will include procedures that their child finds distressing. Thus, it is important to understand parents' experiences of this, the implications of the situation (e.g. impact on the parent-child relationship), and the parent and child's associated support needs.

Currently, there is insufficient evidence about the range of factors that must be considered to design a more comprehensive study of these issues. Therefore, this research was funded with the objectives of providing the 'exploratory groundwork' to inform future research. It would also provide a preliminary evidence base to inform best practice for supporting families in this situation. Three questions guided the research:

- What are parents' experiences of administering nursing and healthcare procedures that cause their child distress as part of caring for them at home?
- When parents are responsible for administering these procedures, what is the perceived impact of this on the parent-child relationship, parental and child wellbeing, and the family?
- What are the support needs of parents with this responsibility, both at the point of being trained and prepared to undertake such procedures, and in the longer-term?

CHAPTER 2: OVERVIEW OF METHODS

In this chapter, we provide an overview of the methods used.

Design

An explorative, qualitative study is the appropriate research design when there is no, or extremely limited, existing evidence. Semi-structured interviews, consisting pre-dominantly of 'open' questions, are commonly used in explorative, descriptive studies. They offer an effective means of collecting rich, detailed information about under-explored topics.[32] This was the design chosen for this study.

Data collection

A topic guide was used to facilitate interviews and ensure consistency of the issues covered. All interviews were undertaken either in person or via telephone, depending on parents' preference, and lasted between 39 minutes to 2 hours and 25 minutes. Interviews tended to be longer for those that took place in person, but we did not observe any noticeable difference in the quality of data collected between the two modes. Interviews also tended to take longer for those discussing multiple procedures (an average of 81 minutes in length) than those discussing one procedure (an average of 57 minutes in length). Interviews were recorded with permission and were transcribed verbatim.

Sampling and recruitment

We intended to recruit twenty parents who were *currently* undertaking procedures, or had done so in the past three months, as well as up to 10 'second informants' from the household (e.g. second parent, or grandparent), who either shared responsibility for the procedure or were present but had no active involvement. Part way through the recruitment period we extended our recruitment criteria to improve participation rates, by including those who were no longer carrying out procedures but had done so at any point in the past (as opposed to the past three months, as originally intended).

Parents were eligible to participate if they were undertaking, or had done so in the past, procedures that *they* thought their child found distressing, *and* if their child was aged 10 years or less. We purposefully wanted to avoid interviewing parents of older children because we hypothesised that issues relating to puberty may have added another layer of complexity. As there were already a number of issues we wanted to explore with the topic, we did not feel it was possible accommodate this additional question in the current project. In addition to these core eligibility criteria, we wanted to sample parents to represent a range of factors so we could explore these in the study. These included:

- A range of ages between birth and 10 years.
- Children with and without cognitive impairments.
- Children with both sudden onset conditions and conditions present from birth.

- Parents who did and those did not share responsibility for the procedures with a family member.
- Both long and short durations of holding responsibility for the procedures (defined here and less or more than 6 months).

Participants were recruited through an advertisement (see Appendix 1) placed on social media sites and also distributed via email newsletters (see Box 1).

Box 1. Places where the recruitment advertisement was posted

WellChild closed Facebook page, local branches and email list
 Together for Short Lives newsletter
 Children's Heart Association website
 Cerebra Facebook page
 CLIC Sargent Facebook page
 Lagan's Foundation Facebook page
 Tweeted from SPRU and WellChild Twitter accounts
 Distributed via SPRU's Parent Consultation Group

The recruitment advert briefly explained the research and included a link to an information leaflet (Appendix 2) (with details of the research and eligibility criteria) and an online response form (Appendix 3) where parents were requested to provide further details and their contact information to register their interest in participating. The items on the response form captured those factors listed above for which we wanted to purposively sample. Had we had over-recruited, we would have used this information to be more selective and ensure an equal spread across all factors. However, due to the difficulties in recruiting we accepted all those who met the core eligibility criteria. Nonetheless, we were able to achieve a spread within the sample on most of the factors listed above.

Those who were eligible were contacted to discuss the research and if they agreed to participate, interviews arranged. Those who were not eligible were also contacted to explain this and thanked for their interest. A total of 17 parents contacted us this way, and of those 12 took part in the study. The reasons for the remaining five parents not participating in the research were: agreed and then later withdrew, (n=1); research team unsuccessful in making contact (n=3); initial contact with parent revealed not eligible to participate (n=1). A further three participants were recruited via the researchers' existing networks and contacts.

Recruitment of 'second informants'

As noted above, we wanted to recruit to the study up to 10 spouses/partners who either did or did not share responsibility with the other parent for carrying out the procedures. Of the 19 parents interviewed, 17 had spouses. Two parents asked we did not make contact due to their partner being too busy. We sent information to the remaining 15 spouses, and five of these agreed to participate.

Sample size and characteristics

Nineteen parents were recruited to the study, plus five 'second informants', all of whom were spouses. Thus, the total sample was 24 parents, including five couples. Table 1 below sets out the characteristics of the parents recruited to the study and the children and medical procedures represented.

Table 1. Sample description

	Number of parents who were:
Mothers	18
Fathers	6
Single	2
Married or living with a partner	22
Age range of parents	27-64 years
Age range of children at the time of being recipient to the nursing/healthcare procedures	3 months to 11 years
	Number of children with:
Sudden onset conditions	5
Conditions present from birth	14
A lot of difficulties with learning and communications	9
Some difficulties with learning and communication	3
No difficulties learning and communication	6
Conditions of children represented in the sample (some generalised if very rare): Brain damage; cancer/ leukaemia; cerebral palsy; cloacal anomalies; congenital heart conditions; low immunity; lung disease; neuro-degenerative conditions; rare chromosome conditions; undiagnosed	
Procedures parents carried out:	
Inserting naso-gastric tube	9
Changing and routine care of tracheostomy tubes	5
Insertion or changing of gastrostomy feeding tube or button	5
Finger/thumb pricks	4
Other nasal procedures such as inserting naso-pharyngeal airways and prongs, nasal suctioning and nasal cannulas	4
Injections	2
Changing of dressings	2
Oral suctioning	2
Bladder manipulation	1
Colostomy care	1
Suppositories	1

Analysis

The first stage of analysis involved repeated reading and annotation of the transcripts to aid familiarisation with the data. This annotation was done both on the hard copy of the transcript, and later using post it notes. Large sheets of paper were used for each interview, and the post-it note annotations affixed to each, with notes categorised into three sections, one for each research question. This was a useful method for familiarising ourselves with each transcript.

In the research proposal, we stated that we would use the Framework approach (Ritchie & Lewis, 2003) to support a thematic analysis of the data. However, upon starting this, it was clear that this approach was not suitable for the complexity of the data we had collected. Parents' accounts were multi-layered, strong in their narrative style (that is, there was often a story being told about their experiences) and deeply rooted in context. As such, separating the data in the manner of theme-by-participant matrices (as per Framework) at such an early stage in the analysis would mean much of the narrative, complexity and context would be lost. Thus, we adapted our approach.

To retain the narrative of each interview and the complexity of parents' accounts, we prepared a 'pen portrait' of each interview. This involved taking the interview transcript and condensing it into a narrative about the parents' experience, using quotes and transcript page numbers as a reference. These portraits were usually between three and five pages long, and the narrative was organised into five sections (*the participants' circumstances, how they came to have responsibility for carrying out the procedures, and the three research questions on experiences, perceived impact and support needs*). Each portrait included a series of bullet points summarising the main themes and issues emerging from the interview.

The next level of analysis involved further condensing and summarising the themes and narratives of the pen portraits. For this we used MindGenius® software, a tool for mind mapping. Mind maps were created for overarching themes, with sub-themes and related issues as branches. Data were summarised from the pen portraits onto the mind maps, with interview codes used on the mind maps for tracking and audit purposes. A list of the mind-maps, which reflect the overarching themes and categories, is provided in Box 2. These mind maps, in conjunction with the pen portraits, were then used to guide a thematic analysis. This involved writing analytical notes which comprised thick layers of description about the themes, patterns and typologies. As part of this, we compared groups and examined cases to seek explanations for the findings.

Box 2. Mind map main themes and categories (used to guide the thematic analysis)

1. How did parents come to have responsibility for the procedure
 2. What is it like for the parent
 3. Managing the situation (self, child, siblings, environment, spousal divisions of responsibility)
 4. Perceived acceptability of having this responsibility
 5. Implications for the parent-child relationship
 6. Training and preparation for the procedures
 7. Ongoing support
-

Ethical considerations

Approval for the study was obtained from the University of York's Department of Social Policy & Social Work Research Ethics Committee prior to the commencement of the research. A record of informed consent was obtained from all participants prior to interview. For face to face interviews, this was a signed consent form. For telephone interviews, we audio recorded the participants' verbal consent. All participants were offered £20 cash as a thank you for their participation. In three cases, parents asked us to donate this to a charity of their choice on their behalf.

We anticipated this to be a particularly sensitive topic to interview parents' about and in preparation for this, we put in place various strategies:

- Information about the purpose of the research and content of the interviews was clearly set out in the Study Information Sheet provided at recruitment and again when participants agreed to participate) and also discussed when the researcher made contact with a parent to arrange an interview.
- The interview was structured in such a way that the interview 'eased' into potentially sensitive topics and concluded with lighter, less sensitive topics.
- Prior to interview we ensured participants were informed that they could pause the interview if they wanted, or end it completely if they changed their mind at any point in the interview. None chose to end the interview, and the only times breaks were taken during interviews was for reasons other than participant distress (e.g. seeing to children, answering the door).
- Strategies for managing distress were discussed by the research team in advance of commencing interviews. In a minority of cases, participants did become momentarily upset when discussing and recalling aspects of their experience. This was sensitively acknowledged, and participants were asked if they would like to pause or break the interview. None chose to do this and wanted to continue telling us about their experiences. In these instances, we followed the participants' preferences to continue. We were confident that no interviews ended on a negative note and no participants were left in distress.

- All participants were given a support leaflet after the interview, containing information and contact details for sources of national and local support (e.g. helplines, voluntary sector organisations).

The wider context of the parents' lives

For the parents who took part in this study, their role as their child's primary carer meant that the procedures they carried out were just one part of a bigger caring responsibility. Taking on these procedures could also shortly follow their child's birth or diagnosis, and so began in tumultuous circumstances where there were many other (often more significant) issues to contend with. Ultimately, carrying out procedures that caused distress for their child was situated within the wider context of their child's illness and care needs. It is important, therefore, to consider the following findings not as a representation of parents' *entire* caring experience, but as one component of it.

In the following chapters (3-7), we report findings about how parents came to have responsibility for these procedures, the training and support they received, what issues they had to manage resulting from their child's distress, and how they think it affected them and their relationship with their child.

CHAPTER 3: TAKING ON RESPONSIBILITY FOR THE PROCEDURES

When parents took on responsibility for these procedures, it was either through a proactive choice to do so, or with little to no choice because it was required of them due to force of circumstance. In this section we present findings about these different routes to taking on the procedures, and the initial concerns parents had.

Parents proactively choosing to take on responsibility

For those who proactively chose to take on procedures, this decision was shaped by two key factors. First, some parents were required to take their child to hospital each time the procedure was required, for a ward nurse to carry it out. To avoid lengthy trips to, and time spent in, hospital, which could result in family fragmentation, they instead chose to carry out the procedure themselves at home. The sorts of procedures represented among this group of parents were injections or (re-)passing naso-gastric tubes. Second, parents felt it was better for the child that they, rather than a nurse, carried out the procedure. In these instances, parents described situations in which their child had become very distressed when nursing staff had carried out the procedures. In response, parents felt it would be better for them to deliver such care, because, as a comforting, familiar and trusted figure, they could do so in a way that was less distressing for the child:

“I just thought well if it was me I'd much rather my mum did something like that than someone I've never seen before (laughs) leaning over me and poking a tube up my nose, I'd rather it was someone I trusted...”
Interview 16, inserting a naso-gastric tube¹

“[when the nurses inserted the naso-gastric tube] there wasn't the talk and the communication, there, there wasn't the reassuring, it was kind of occasionally there'd be, it's OK [child], and then nothing and just carry on what they're doing, whereas when I was doing it, it was 'It's all right darling, it's mummy, mummy's here, I've just got to put this in here.' So even if she didn't fully understand she could hear my voice and it was mummy and it was all about the reassurance” Interview 4, inserting a naso-gastric tube

Where parents had chosen to carry out the procedures, their accounts suggested that they were making trade-offs between what was emotionally comfortable for them and what they felt would bring wider benefits (see Box 3).

¹ Quotes are used throughout the report to illustrate the reported findings, and are attributed to the interview number and the procedure being referred to.

Box 3. 'Trade-offs'

It is unpleasant to do these procedures but...

- It is better for the child as a parent can make it less distressing than a nurse
- It avoids lengthy and multiple trips to hospital (e.g. when a tube falls out), which in turn:
 - Minimises family fragmentation
 - Keeps the family at home

This notion was echoed amongst others, who – although they had not *proactively chosen* to take on the procedures for these reasons – believed it was still 'better' for a parent than a nurse to do so. Again, this was because they felt they were a comforting figure to the child, or that as a parent they knew best how to calm their child. For example, in one instance, a traumatic experience had led to a child developing a negative association with healthcare professionals, and the mother felt she was a 'nicer' alternative to carry out the procedure:

“although it's not nice for a parent to have to do, and I think like that, for a child it's gotta be a lot nicer than someone marching in in a uniform, which is, as soon as she sees someone in a blue t-shirt I think she thinks oh, here we go.” Interview 5, changing tracheostomy tube

Parents who had taken on responsibility for procedures due to force of circumstance

For those who did not perceive themselves as actively choosing to take on the procedure(s), one of three scenarios led to them assuming this responsibility.

First, for a small number of children with tracheostomies who were inpatients, taking on responsibility for the procedures was a condition of discharge. In these cases, responsibility for the tube changes either transferred to the parent soon after the tracheostomy was fitted or gradually shifted from a ward nurse to the parent over the period of time the child was in hospital.

Second, as soon as the child required the procedure it immediately became the responsibility of the parent. Again, this included children with tracheostomies who were inpatients, and also those requiring finger or thumb pricks who were already discharged. In these instances, parents saw it as an expected part of their role – “it's just part of what needs to be done” (Interview 6, finger pricks).

Third, parents reluctantly took on responsibility for the procedures when there was no professionals trained to do so – “our local hospital does not deal with gastrostomies at all”

(Interview 14, inserting gastrostomy tube), or because the community nursing team was unable (e.g. due to time pressures or availability) or appeared unwilling to help:

“... our community nurses came along and, and, and did it once a week, at least did it once a week for us, but unfortunately, well unfortunately, they said ‘No, we're not gonna come out anymore and do it, you know, it's up to you, you to do it’” Interview 20, changing dressings

“it was really hard to get ‘em to come out when, when I needed ‘em to, and when they did come out I felt under pressure that I should be learning myself” Interview 14, naso-gastric tube

In these instances, the procedures were either carried out by community nurses until parents took them on, or immediately became the responsibility of the parent on the child's discharge from hospital.

Parents' early concerns about assuming responsibility for the procedures

Parents recalled having concerns during the period in which they were being trained for and/or took on responsibility for a procedure. Parents responsible for particular types of procedure (e.g. naso-gastric tubes, giving injections or changing tracheostomy tubes) typically reported having concerns about ‘getting it wrong’ and the safety implications of this, and a need for reassurance. The responsibility for a procedure that maintained their child's life, or was potentially life threatening if mishandled, was daunting. For some, this was exacerbated by the child being discharged home for the first time.

Concerns relating to the distressing nature of the procedures for the child were threefold and were not associated with technical concerns about administering the procedure correctly. First, there were apprehensions about how to manage physical or verbal resistance. Second, there were fears about causing their child distress because the procedure(s) was painful or physically uncomfortable. Third, there were concerns about how to manage siblings, not only in terms of supervising them/managing their presence during the procedure, but also how they might react to seeing their brother or sister upset.

To varying extents, these concerns were lessened over time. Sometimes the training and preparation parents received served to address them, to at least some degree. Furthermore, parents typically reported adjusting and adapting over time to the demands the procedures place on them. However, this was not always the case and we return to this issue later. In the next chapter, we describe the initial training parents received and if and how they reported it prepared them for carrying out the procedures at home.

Summary

- Some parents had a choice in taking on responsibility for carrying out the procedures, whilst others did not.
- Where parents did not have a choice, this was sometimes because of limited service provision locally.
- Where parents chose to take on the procedures, they made trade-offs between their own emotional discomfort and wider benefits to their child and/or family.
- The key concerns parents had in taking on responsibility for these procedures at home were: how to manage physical and verbal resistance from their child, handling their child's distress, managing siblings who would be present, and the safety implications of incorrectly carrying out the procedures.

CHAPTER 4: TRAINING AND PREPARATION FOR THE PROCEDURES

Most parents interviewed underwent training for the procedures in hospital, which was in all but one case led by ward nurses (in one case, a surgeon). A minority were trained at home by a community nurse while some described initial training in hospital with follow up training at home.

Parents had varied experiences of the training in the procedure(s) they were taking responsibility for, both in its extent and quality. Views about how helpful (or not) the training and preparation was centred on six main issues:

- Pacing
- Extent of training
- Addressing management of distress or resistance
- Provision of information
- Setting
- Staff attitudes

Pacing of training

A key feature of the accounts of parents who reported positive experiences of being prepared for and trained in the procedures was that it was paced in such a way to give them confidence in their abilities to carry out the procedures. Repeated demonstrations by nursing staff were also reported to be helpful, as was the opportunity for lots of practice observed by staff when needed. This type of preparation tended to be described by parents who trained for procedures whilst in hospital awaiting their child's discharge. The period of time in hospital prior to discharge also provided time for parents to talk through anxieties they had about the procedures. Other parents, however, felt their training was rushed and limited, leaving parents uncertain and lacking confidence.

Extent of training

Concerns were also raised about the extent of training. In some cases, parents had received an initial period of training but no further follow up or refreshment of competencies. They compared this to the ongoing training of their paid carers for carrying out the same procedures:

“Very frustratingly, sometimes a support worker'll come in and say ‘Oh this has changed’. And I'll say ‘Has it?’... So they, they'll get updated, we don't always get those updates as well, so it's kind of left up to us to kinda say ‘Well hang on a minute, has this changed?’ And so ‘Ooh yes, we forgot to tell you’.” Interview 5, various procedures

Some suggested there would be value in having intermittent observation and supervision from nurses after the initial training period. This would serve to refresh parents' competencies in administering the procedure. Some felt that such intermittent observation and supervision would have been useful in the earlier stages of carrying out the procedures, whereas others indicated it would be valued at any time. In line with this, questions were raised about *who* was accountable following training to ensure parents remained competent.

Addressing management of distress or resistance

Parents reported that their training had tended to focus on the technical aspects of carrying out the procedures. Only in some cases was attention given to how they would manage their child's distress and/or physical resistance, where this was addressed the advice was given by ward nurses, and in one case a play therapist. Some parents noted that they would have valued guidance about this at the training stage. Others recalled applying more general advice about supporting their child which they had received from health professionals (e.g. using praise and rewards) within the specific situation of managing their child's distress during procedures.

Provision of information

It was also important that those training included detailed demonstrations and information (including written) about the procedures. This included information about why parents were undertaking the procedures, how to undertake them, and what to do in times of uncertainty. Parents also expressed a need to be more informed about the child's condition and healthcare more generally. Examples parents gave about this included having questions about what dressings to use, naso-gastric feeding options, monitoring oxygen levels, and what to do in response to changes to the child's heart rates and temperatures.

When parents had these information needs (whether specifically about the procedures or more generally about the child's health and care), some accessed instruction from health professionals, including ward and community nurses and also doctors. Others described a gap in professional support in this respect, and turned to other sources of advice and information instead. For example, some used websites, Twitter and online support forums to ask questions and seek advice about the procedures and other aspects of their child's care, or drew upon information leaflets produced by NHS trusts (for example, GOSH). Written information was thought to be particularly helpful to refer to at a later point, especially when feeling too overwhelmed to absorb information during the training period:

"I remember like us going back and questioning was that what they actually said and, and I think being given, cos when you're told these things it's so overwhelming and you're worrying about listening and writing it down, have you written it down right; I think being given a written document explaining exactly how you do it from literally everything, put on your gloves, do this, do that, literally written down

everything exactly how they do it I think would, would have helped.”

Interview 17, injections

It was also important that training finished with the contact details of people who parents could access for further help, information and advice if needed (for example, a community or ward nurse). These served to enhance parents’ confidence in carrying out the procedures when they eventually did so at home.

Setting

For parents who had been trained in a procedure in hospital, the issue of privacy was sometimes raised. Practising in the ward environment could leave parents feeling exposed when others on the ward were observing their struggles to learn the procedure and manage their child’s distress.

Staff attitudes

Parents said they valued the reassurance and encouragement given by nurses during training as it helped to allay their anxieties. Some felt that the nurses who had trained them had been particularly helpful in this respect. Others, however, described experiences of staff being insensitive to their child’s distress, with unfair expectations of how this should be managed. The accounts of some parents highlight how their own emotional discomfort at carrying out a procedure that caused distress for their child was not recognised during the training period. Parents felt it was important for staff to recognise this and allow ‘time out’ from practicing if needed.

A summary of good practice for training is detailed in Box 4 and the vignettes below present the ‘best’ and ‘worse’ case scenarios for training, preparation and advice based on the accounts of those we interviewed.

Box 4. What does good training and preparation look like?

- Paced, not rushed, giving parent enough time to become confident
- Lots of practice with observation from nurses when requested
- Staff going through the procedure with parents multiple times
- Being given reassurance
- Having the opportunity to talk through anxieties about doing procedure
- Lots of detail, demonstration and information
- Written information about the procedures
- Advice and tips about managing child's distress and reactions
- Staff being sensitive to the child's distress and how parents handle this
- Staff recognising parents' emotional discomfort (and allowing parents 'time out' for this if needed)
- Ensuring privacy when practising procedures on the ward
- Provision on contact details of staff for further help or advice

Example 1: Good training and preparation

Sally's eldest son was born with multiple health needs and he required a tracheostomy from early infancy. She began learning how to clean, care for and change the tracheostomy tube whilst her son was in hospital. The training was paced, detailed and thorough, with the nurses encouraging mum each time she practiced. Sally liked that she could have a nurse with her to practice, and that sometimes she could practice on her own, knowing there were staff nearby at the nurses station if needed. The nurses told her she could take as much time as she needed to train, and her son would not be discharged home until mum was confident she could manage. Sally was anxious about the distress that changing the tracheostomy tube seemed to cause her son. She found it helpful to talk about this with a ward nurse, and was given some tips on ways to comfort and soothe her son during the procedure. Upon discharge, Sally was given the numbers of the ward staff and was told she could ring at any time. There were also regular visits by a community nurse in the earlier stages of being at home.

Example 2: Poor training and preparation

Helen became responsible for passing her two-year old son's naso-gastric tube after he was diagnosed with leukaemia. Her son didn't like having the tube inserted, and she was reluctant to be the one to do it. She felt she had no choice as there was no community nursing service available to do it. Helen was given the training on the ward, but there wasn't much privacy and she felt exposed. It was difficult getting it right, and her son became increasingly upset. The lack of privacy made the situation worse. It all felt a bit rushed, and she got the impression the nurse didn't have much time. There wasn't much opportunity to ask questions, and so when Helen and her son went home, she was left feeling anxious about whether she would get it right and how to calm her son. She was especially concerned about what she would do if she needed to restrain him if he became really upset, because there was only her in the house – it seemed to be a two-person job. Although she had the number of the local community nursing team, they had always been too busy to visit, and so Helen felt she has been "left to get on with it" on her own.

Following training, most parents went on to begin carrying out the procedures for their child at home. For a minority, parents carried out the procedures in hospital (e.g. if awaiting discharge) before then doing so once at home. Once the child was home and the parent began carrying out the procedures, various forms of ongoing support were noted as important, which we highlight in chapters 5 and 6.

Summary

- The extent of training received by parents varied, with some experiencing limited, one-off training whilst others were prepared over a longer period of time.
- Good quality training was comprised of a number of facets: it was more than a one-off event, it allowed parents time to practice and grow in confidence, addressed parents' anxieties and provided reassurance, included advice about ways to manage the child's distress and resistance, recognised the emotional discomfort such procedures may cause parents, and finished with the contact details of available nurses to call for advice if needed.
- Once the initial training was complete many parents expressed a need for ongoing reassurance and 'top up' training, or checks that they were still carrying out procedures correctly, in the longer-term.

CHAPTER 5: PARENTS' EXPERIENCE OF CARRYING OUT THE PROCEDURES AT HOME

Carrying out the procedures was a technical process (for example, setting up equipment, testing that tubes were in the correct position). However, because the procedures caused distress for the child, parents faced additional issues. These included managing their child's distress and resistance and the reactions of siblings present in the home. In this chapter, we report findings about this, focusing on: parents' views on their child's distress, how distress and resistance was managed, and views about managing the presence and reactions of siblings. To begin, however, we provide an overview of how responsibility was shared between parents.

Sole or shared responsibility for procedures

The majority of our interviewees were in two-parent families and, of those, just under half shared the responsibility for the procedures to some extent with their spouse. Sometimes fixed roles had been assumed (e.g. one parent always being responsible for distracting or holding the child, whilst the other administered the procedure), in other cases parents took turns with the different roles required. Where responsibility was shared with their partner, parents valued this. It offered a sense of shared responsibility, a way to give each other reassurance, and, for a minority, avoided the concern that their child would see them as the 'bad one':

"if I'd been on my own, having to do it on my own, I would have felt a lot more isolated. I'd have felt like [son] might have just thought it was me, like maybe would have looked at, just at me as the bad person, you know, like it was just me that was the one that was inflicting this" Interview 17, injections

Some mothers in two-parent families, however, did not want their partners involved, feeling it would disturb the routine they had established with their child, or because they felt it was their responsibility as a mother.

Where responsibility was not shared, this typically reflected family and household circumstances, such as being a single parent, or working arrangements (e.g. the spouse, often the father, working full time or away from home). In a minority of cases, it appeared the spouse (mother or father) had chosen not to become involved in administering the procedure.

Parents' reports of their child's distress

As noted at the start of this report, we set out to recruit parents to the study who were carrying out procedures that *they* thought caused their child distress. Some parents ascertained this through their child's verbal communication, whilst others relied solely on

their child's behavioural cues (for example, where the child was non-verbal). Some parents also appeared to use their own experiences of the procedures to infer how their child might find it:

"I think it [nasogastric tube] hurt... I've had it done myself and it's not, it's horrible" Interview 14, nasogastric tube

Before continuing, there are four points to note about how parents reported their child's distress. First, most of those interviewed indicated it was the procedure itself which caused distress. However, some noted that the child's distress was caused by the anticipation of the procedure, or the restraint needed to carry it out. Second, the child's distress was short lived, with parents observing that their child became calmer once the procedure was complete. Third, parents reported that, in most cases, their child's distress eased over time, and we come back to this issue later in the report. Fourth, some felt the child's cognitive development played a role in their experience of distress. Older ages, for example, and perceived higher levels of cognitive awareness meant a capacity to remember what the parent is doing, whereas younger ages did not. Such capacity to forget was linked to distress being only momentary, and thus easier to manage:

"he would just look up, lie on his bed, do, do some intervention with him, he'd scream and then he's all right, within a minute of that and he'll be fine, he'll be back to his usual self, and then he would forget about it."
Interview 8, inserting nasogastric tube

Because of the subjectivity of the child's experience and how parents interpreted this, each described their child's distress in different ways. Below, and in terms of the most commonly represented procedures in this study, we provide an overview of parents' perceptions of how their child experienced a procedure.

Passing nasogastric tubes and other nasopharyngeal procedures

These tended to be described as being "unpleasant", "upsetting", "stressful" or "uncomfortable" for the child. None described it as being painful for their child, and some stated explicitly that it was uncomfortable rather than painful. Behavioural cues indicating the distress included their child squirming, wriggling, flinching, screwing up their face, arching their back, their body going tense, going red, gagging/retching, turning their face away and banging their head. Screaming and crying were also described as responses, as well as the child 'going mad', fighting it, and attempting to scratch the parent.

Changing tracheostomy tubes

These were typically described as "invasive" and "uncomfortable" rather than painful. This was linked to the temporary removal of the child's airway, being touched, having to be put into an uncomfortable position, and/or being restrained in some way. Behavioural cues of

distress included increased heart rate, choking, coughing, wriggling, shaking their head to indicate 'no', avoiding eye contact, going quiet and flinching.

Insertion or changing of gastrostomy feeding tube or button

These were described as being "painful" or "uncomfortable", with variations in the extent of this (from causing a little distress to inducing screaming and crying). Behavioural cues of distress included the child going rigid and stiff, tensing their stomach, rolling away, thrashing around, twitching, and pulling the parents' hair. Screaming and crying were also described as responses.

Finger/thumb pricks and injections

These tended to be described as "painful" and/or "stressful" for the child. Some described their child protesting verbally in anticipation. During the procedure, behavioural cues of distress included their child turning away their hands, hitting out, and not talking to or looking at the parent. Crying and screeching were also described.

Despite the variation in how parents described their child's distress, all indicate their child had exhibited distress to some degree, indicating the child did not like what was happening during the procedure. The verbal and behavioural cues of this distress were largely homogenous across the procedures, though some subtle differences are apparent. Even so, it is not possible to infer from this whether some procedures are typically 'more' or 'less' distressing for children.

How did parents manage their child's distress?

The distress that parents felt their child experienced as a result of the procedures was central to the experiences of many of those we spoke to, and it was clear that being able to prevent and manage such distress was important. Some were offered advice about this at the training stage, or sometime after, whilst others were not. For those who were not given advice, there was mixed views about whether this would be welcome. Some argued that parents are best placed to develop strategies to manage their child's distress, but the expressed need for such advice from other parents we spoke to indicates that some parents, at least, would welcome input on this from professionals. Regardless of whether or not parents were given advice, most had tried, used or developed techniques to minimise their child's distress from the procedure, although the extent to which these were felt to be successful varied.

The most common method of trying to prevent and reduce child's distress during procedures among those interviewed was distraction. Methods of distraction included uses of tablets on which children could watch something or play games ("*a godsend... the best distraction tool*"), overhead mobiles, and splitting parental responsibility so that one parent distracted the child whilst the other carried out the procedure. Parents also described efforts to make the procedure into a game, which could distract the child (e.g. by making

them laugh), though one parent noted this was easier when there are two parents involved. For a minority, distraction was seen to be ineffective, and some linked this to the child's age, although there were contrasting views about this. In one case, distraction was thought ineffective *until* the child became older, whilst another felt it was only effective whilst the child was younger.

Getting the child involved was also a strategy used, and was seen to afford the child some degree of control over what was happening. Methods of involving the child included getting them to prepare and use the machine for finger pricks, or holding and removing needles. Others described how giving a treat or bargaining with their child sometimes, but not always, helped to manage their distress and facilitate their child's cooperation with the procedure:

"I say to her "then you can have the magic box afterwards and there'll be a present in there" and she'll agree. So that, in that sense it's got easier, cos she knows that, oh something bad's gonna happen but I'll get something nice afterwards. That's really the best way I've found of handling it."

Interview 5, various procedures

Explaining what was happening and verbally reassuring the child was a method used by some parents, though one parent had found this did not seem to alleviate their child's distress. Another described how this was the *only* method they could use to calm their child as all hands were occupied in carrying out the procedure. The child's age or perceived cognitive ability appeared to shape the perceived success of strategies such as these. When children were older or more cognitively aware, this made it easier for parents to reason with, and explain what was happening to, their child:

"she'll openly admit she's got a better quality of life now, she'll say to you, you know "If you fail, you know, if I don't do this what'll happen?" So I said "Well we'll just end up in hospital all the time". So and I think that's best, cos she is ten she has got more of a, you know, an idea about it." Interview 2, injections

Other strategies to prevent and manage the child's distress reflected activities to prepare the child, including having a known routine for the child, which was thought to help the child relax, and allowing the child to give their mother finger pricks as a means of demonstrating that it did not hurt. Importance was also placed on allocating sufficient time to undertake the procedures so that they are not rushed and/or doing so at a designated 'quiet' time (e.g. when there is no one else in the house). These efforts were felt to help both the parent and child to stay as relaxed as possible. In two cases, parents struggled to find any method that helped to make the procedure less distressing for their child.

Box 5 lists the main techniques used to prevent and manage the child's distress.

Box 5. Techniques used to manage or prevent the child's distress during procedures

- Distraction (IPads, television, over-head mobiles, other parent)
- Making it a game and/or getting child involved
- Allowing child to try finger pricks on parent
- Carrying out procedures at a designated time
- Bribery and rewarding
- Explaining, reassuring
- Regular routine regarding the way the procedure is administered
- Allocating sufficient time to carry out procedures

Resistance and restraint

Many parents described how their child, on some occasions, had or would physically resist the procedures, and so some form of 'restraint' became necessary. Various methods were used, from swaddling (inserting tracheostomy and naso-gastric tubes), holding child firmly on one's knee (finger pricks, injections), holding the child's head or hands, cradling the child (inserting naso-gastric tube), or using one's legs to hold the child (inserting a gastrostomy tube). Sometimes these were used preventatively, rather than once the child began to physically resist. Managing a child who was physically resisting a procedure was often described by parents as a 'two person' job, and could therefore be a struggle for those who were carrying out the procedures alone (for example, single parents or where one parent is at work). Indeed, some parents expressed a need for assistance from health staff to act as a second pair of hands in these contexts. In some cases, the restraint itself was thought to upset the child, or be more distressing than the actual procedure, and this too was a concern.

Parents' accounts suggest that managing physical resistance could become more difficult as the child became older or stronger. Here, restraining their child became more challenging for parents, adding to the emotional discomfort they felt.

Managing siblings

Some of those interviewed had other children who were at an age where they could not be left unsupervised. In these instances, parents had to think about how their presence should be managed during the procedures. There were contrasting views about what was acceptable or required. Some felt it was better with other children being occupied elsewhere. For example, one parent had the sibling occupied by the father in another room, whilst another preferred to wait until her other son was at nursery before carrying out finger pricks. Another noted an instance where she asked another family member to occupy and supervise the sibling. Others did not have the option of having brothers or sisters supervised elsewhere by another person. Thus, if they were a single parent or if there was no other family to help sibling presence during procedures was something that could be a

necessity rather than a choice. A further group of parents positively chose to allow their other children some involvement or exposure to aspects of their child's care as a way of making them more informed. For example, this mother describes how she allowed her other child to watch the administration of medications and encouraged involvement in the local St John's Ambulance from an early age:

"...he was seeing high level nursing and medical procedures, and on, on his brother he was seeing me doing them and I wanted to demystify it a bit, I wanted him to understand what was happening and why, and that, that actually worked really well" Interview 3, various procedures

One parent reported being given advice by a nurse about managing the presence of her other child, suggesting the use of distraction through a portable tablet. This was felt to be a useful technique for keeping her other child occupied during the procedure.

Summary

- Responsibility for the procedures could be shared between parents, or solely the domain of one. There were contrasting views about what was preferred.
- In addition to coordinating the technical delivery of the procedure, parents had to manage their child's resistance and distress (both in anticipation of and during the procedure).
- Parents used various techniques to make the procedures less distressing for their child; the extent to which these were felt to be successful varied, and some wished for advice about ways to manage this.
- There was an expressed need for assistance with restraining their child.
- Age and cognitive ability of the child were linked with the perceived success of some strategies parents used to minimise their child's distress.
- Where there were other siblings at home, parents had to make decisions about their presence, whilst others had no choice about this.

CHAPTER 6: PARENTS' EXPERIENCES OF BEING RESPONSIBLE FOR A DISTRESSING PROCEDURE

In this chapter, we report findings about parents' experiences, in terms of how they thought being responsible for these procedures affected them emotionally, how they managed their own responses, and how this changed over time.

Parents' emotional responses

For most, but not all, parents we interviewed their role in carrying out a procedure that caused their child distress was an emotional experience, and they indicated discomfort or unease with the responsibility. This was evidenced in the words they chose to describe how it felt for them, as parents, to carry out these procedures: "upsetting", "awful," "really tough", "unpleasant", "horrific", "horrid", "horrible", "horrendous", "stressful", "not nice", "traumatic" and something they "hated". This emotional discomfort was caused by the perception that they were doing something that resulted in observable pain and/or physical discomfort, and/or that they were *possibly* hurting their child:

"she screwed up her face and I felt I was hurting her; and that was horrid"

Interview 16, inserting naso-gastric tube

"when she was little it was even awful doing the tracheostomy, with all the training I had on that. She just used to cry all the time and I just thought I was hurting her; I don't know if I was hurting her or not" Interview 7, changing tracheostomy tube

That said, the degree of emotional discomfort varied between parents and also tended to ease over time, though this was not always the case (we return to this point later in this chapter.) Not all the parents we interviewed described their experiences in such emotional terms, and for a minority, it was either unproblematic or the emotional difficulties of carrying out the procedure were dwarfed by bigger demands, such as the burden of being responsible for life saving care, or coping with the child's illness.

Where it had been, or continued to be, an emotional experience because of the distress caused to the child, implicated in this was a sense that parents felt they *had* to do these things and the conflicting emotions this aroused:

"it's probably one of the most difficult things to do as a parent, because you know that if you don't give him it he's not gonna get any better but you know that you've gotta hurt him to get him better" Interview 10, various procedures

For some, there was a sense of dread in anticipation of carrying out the procedures. Afterwards, there could be feelings of guilt, which could be linked to conflict about their role:

“Oh it, it’s the guilt all the time, because it goes against the grain; you’re, you’re, you’re there to look after your child and you’re doing all these things so that you can look after your child, but at the same time it, they’re not nice things, they’re, they’re quite horrible.” Interview 3, various procedures

Parents’ efforts to manage their emotional discomfort

Where parents’ did experience emotional discomfort or dis-ease, there was a need to manage their emotions in order to carry out the procedure.

Notions of disconnecting from the parent role were expressed, with phrases such as going into “nurse mode”, becoming “somebody totally different”, or getting “out of the mother zone” being used. Disconnecting from the parenting role was always described as something utilised *during* the procedure and never afterwards. It appeared to be a way of not having to engage emotionally with what was happening:

“you just have to become somebody totally differently, you can’t be like the gentle mum that wants to give your child a hug because otherwise it just wouldn’t be nice for either of you” Interview 2, Injections

Similarly, some described strategies of blocking out emotions and opportunities to think and ‘just getting on with it’. For some, there was a perceived cycle between the visible emotion of the parent and the extent of the child’s distress, in that an upset parent resulted in an upset child. Thus, efforts were made to mask emotion whilst carrying out the procedures:

"I think one of the most important things was when we realised that if we did this with nervous faces or sad faces she picked up on that straight away, so in both situations, even with the suction machine, I forced myself to smile at her as if it was a nice thing that I was doing (laughs) and not ... not give her the idea that I was anxious or upset" Interview 16, oral suctioning and inserting naso-gastric tube

Coping strategies for after the procedure was complete were also described by some, including having time to oneself, and reminding themselves about why they were doing it and the benefits to the child.

Changes in parents’ experiences over time

For most parents we interviewed, their feelings about carrying out the procedures had changed over time and the emotional impact lessened. This was associated with one or more of the following processes:

- increased acceptance of having the responsibility for administering the procedure;
- a normalisation of the procedure within the parental role and family routines;
- increasing sense of competence in administering the procedure and/or managing the child during the procedure.

Parents reported that there had been a growing sense of acceptance of being responsible for the procedures and/or that the procedures had acquired some degree of normality over time. This was the case even if parents still felt they didn't *like* doing the procedures, and where their acceptance was typified by a discourse of '*I don't like doing this but...*'.

In all the cases where parents had expressed acceptance, the procedures were *not* time-limited. This may partly explain such acceptance – that their responsibility would, whether they wanted it to or not, continue for the foreseeable future. As one mother put it, “we just both know it has to be done”. Another possible explanation is that the frequency or regularity with which the procedures were done meant they become a familiar aspect of parents' wider caring role. For example, one parent described how nasal suctioning was something she initially objected to and refused to do, but now “I've done so many times that I'm not sure I really think about it anymore” (Interview 5). A perceived absence of choice may have also shaped such acceptance:

“Now it's normal for me; before it was like; when she was younger I'd probably think I knew I had to do it, it's you, you know you've got to do it because that's your job now, but you sort of think why should I have to do it? So you question that, and then you think well obviously I have to do it because there's nobody else here to do it” Interview 7, various procedures

Many reported more generally that, over time, carrying out the procedures had become easier, either in terms of the technical aspects, and/or managing their child's distress. A range of factors were linked to this growing sense of competence, most of which were related to the child finding it less distressing. When parents grew more confident, it was felt this made the procedure less distressing for the child because they got better and more efficient with it. The child's growing awareness or compliance made also distress easier to manage, or strategies had helped to minimise the child's distress, making it easier for the parent. This underlines what was highlighted earlier in this section: the extent to which parents felt at ease with doing these procedures was closely linked with the extent of the child's distress.

The role of professional support in assisting parents' adjustment to their new role

Once parents began carrying out the procedures, some had access to ward and/or community nurses for advice and support. Although not explicitly stated by parents, there is some evidence from the data that access to support from nurses may have played a role in helping parents *adjust to the demands* associated with being responsible for a distressing procedure. Some, but not all, of the parents who reported this responsibility had become

easier to carry out perceived their relationships with ward or community nurses as supportive; they reported that these staff asked them how they were coping or provided reassurance when needed. Such opportunities to talk or seek reassurance about their wider caring role may have served to enhance their confidence with the procedures. Not everyone had access to a community or ward nurse, however, and where this was the case, parents typically described being “left to get on with it”.

Even among parents who reported that doing procedures had become easier, or acquired some normality, over time, some felt there would be value in having some form of psychosocial support regarding fulfilling this particular role in caring for their child. In this respect there were suggestions for: access to peer support groups to share similar experiences; nurses to inquire more about how parents feel about doing the procedures; and, support from a professional who had knowledge about the child’s condition but could also offer an empathic, listening ear. Similarly, some ascribed value in nurses simply recognising the responsibility they have for these procedures. By contrast, some of those who had grown confident in the procedures noted they no longer needed support (but stated that it was or would have been valued in the earlier stages of carrying out the procedures).

Parents who reported ongoing difficulties

For a small number of parents we interviewed, their feelings about carrying out the procedures did not appear to have changed over time. Their accounts indicated they had not grown comfortable with certain procedures their child found difficult (passing naso-gastric tubes, inserting gastrostomy tubes, giving injections, and finger pricks), and that it had continued to present an ongoing emotional burden for them. This was the case both where carrying out the procedures was an ongoing responsibility for the parent and for some of those who had carried this responsibility for a time-limited period. Our analysis suggests two possible explanations for this.

First, some of those who indicated they were experiencing ongoing emotional discomfort or struggle with the procedures were those who also described having little, or needing more, support from healthcare professionals. For example, one parent stated a need for more assistance from community nurses in carrying out the procedures, and for them to occasionally ask how she is feeling with her caring responsibilities. An absence of support may make the experience more of a challenge for parents, perhaps because this limits opportunities to talk through anxieties and gain reassurance - features of support that parents described as important. Second, some of those who indicated they had never grown comfortable with procedures were those who had been responsible for them for a limited period of time (for example, giving injections for a year, carrying out suctioning for around five months). Thus, it was possible that, because carrying out the procedures was time limited, there was never the opportunity for parents to get accustomed to them.

Summary

- Carrying out procedures their child found distressing was, for many, an emotional experience. Masking their emotion and disconnecting from their parenting role were ways parents managed how they felt in order to complete the procedure.
- The emotional burden eased for most, with either a growing sense of acceptance and/or a perception that carrying out the procedures had become easier over time.
- In a minority of cases there was a sense that this responsibility presented an ongoing burden or concern. This appeared to be linked to worries about how their child viewed them, an absence of choice in being responsible for the procedures, and/or a need for more support.
- Parents highlighted a need for healthcare staff to acknowledge and offer support to address the emotional side of their caring role. Some also suggested some sort of access to peer support to share experiences would be helpful.

CHAPTER 7: THE PERCEIVED IMPACT ON RELATIONSHIPS WITHIN THE FAMILY

One of our research questions was if and how parents felt their involvement in carrying out these procedures affected their family and their relationship with their child. Indeed, notions of hurting their child and how siblings would react were initial concerns for parents. However, our findings suggest that typically, parents felt their involvement in carrying out these procedures did not impact on relationships within the family. In this chapter, we report findings on this theme.

Perceived impact on the parent-child relationship

We asked parents if and how they felt their involvement in carrying out procedures that caused distress had affected their relationship with their child. The majority of those we spoke to felt that their role in carrying out the procedures had *not* affected their relationship with their child, and that any conflict between them was transient and contained to the period in which the procedure was administered:

“Yeah, I mean it's not had an impact, you know, I mean obviously at the time, she's not very happy with me but it doesn't, she doesn't hold a grudge” Interview 12, finger pricks

Parents attributed this absence of impact to one or more of the following factors:

- Their child being too young to remember what was happening.
- Their child's resilience in being able to “bounce back”.
- The distress being only momentary.
- That there was an established routine for getting the procedure done, and thus was familiar to the child.
- Their child preferred their mother, above anyone else, to carry out what was a necessary procedure.

In addition, and as noted earlier, some had developed strategies for managing their child's distress. In some cases, it seemed such strategies had limited conflict and enhanced cooperation between the parent and child during the procedure. Whilst parents did not state so explicitly, it is possible that successfully managing distress and facilitating cooperation may have helped to limit any negative impact on the parent-child relationship.

A minority of parents did, however, express concerns about how the child viewed them given their role in carrying out the procedures. These concerns included whether the child loved them as much as, or viewed them differently, to the other parent:

“...because if I'm the one that's always passing the, the tube or the, changing the button and daddy's always the one doing the fun stuff near

her face, what must she think of me?" Interview 4, changing gastrostomy button

There were also concerns about whether the child could remember what the parent had done, and whether the child resented or distrusted them because of this particular role:

"I'd go into nurse mode, I wouldn't see [son], I would see the NG tube and the nose, and only afterwards then I could comfort him and be mum. But it, and, and it, it's got to make your child distrust you a bit to know that you're gonna come at them with that tube again, with that needle again"
Interview 3, naso-gastric tube and finger pricks

Sometimes these concerns were exacerbated by the child's inability to communicate to the parent. Others aired concerns that they were seen as nurse rather than a mother, and linked this with a desire for a nurse to carry out the procedures rather than them:

"I mean the fact is that it would have just been, been nice that other people could put it [the tube] back in and, you know, and for them to, to put it back in as well, you know, sort of, I just want, I would rather be a mum than be a medically qualified doctor/nurse, you know, and does, you know, you know, if it did fall out I could phone up somebody and say 'Can you put it back in for me?' So that [child] knows it's not just me doing it or dad doing it, you know." Interview 20, inserting jejunostomy tube

From our analysis of the interview data, it would seem that where concerns were *most* prominent, this was rooted in one or more of the following factors: struggles to manage the child's distress, a feeling of not having any choice to carry out the procedures, and an absence of professional support with the procedure. Whilst a minority of parents expressed these concerns, it is important to note that we found no evidence of deterioration in the parent-child relationship. That is, parents did not describe their child's feelings or behaviour towards them as having changed substantially since they became responsible for the procedures.

Impact on siblings and spouses

As noted earlier, some parents had other children. A minority reported instances where siblings who had the capacity to understand what was happening had expressed concerns about their brother or sister becoming upset due to the parent carrying out a procedure. Parents had managed this by explaining their role to the sibling and all believed this had successfully assuaged these concerns. As a result, none perceived their role in administering distressing procedures as having any sort of lasting impact on their other children.

Similarly, no parents reported their involvement in the procedures, or how responsibility for these was distributed with partners, had affected their spousal relationships.

Summary

- Whilst many parents reported momentary conflict with the child in the run up to, or during the procedure, most did not feel their role in these procedures had affected their relationship with their child
- A minority of parents had concerns about how their child viewed them because of their role in carrying out these procedures. Some parents with these concerns also expressed a desire for nurses to occasionally undertake procedures.
- There was no evidence of a deterioration in parent-child relationships as a result of parents' involvement in the procedures.
- There were no reports that that involvement in carrying out the procedures had affected parents or relationships with their other children or spouse.

CHAPTER 8: DISCUSSION AND IMPLICATIONS

The findings generated from this exploratory study make an important addition to current evidence about the experiences of parents caring for children with complex health conditions at home and ways of supporting them. Past research has identified this as a potential area of concern[1, 3, 8, 11]. This study has offered a more detailed picture of the issues parents face, the concerns they have, and the ways in which they can be supported. In this section, we bring together the findings to answer our three research questions and highlight the implications and recommendations for practice. We conclude with a note about the potential direction for future research on this topic.

What are parents' experiences of administering procedures that caused their child distress, as part of caring for them at home?

Parents became responsible for these procedures in a range of circumstances; some proactively chose to do so whilst others perceived themselves as having less choice. Where parents proactively chose to take on the procedures, they made trade-offs between their own emotional discomfort at carrying out the procedures and the benefits it would bring them and their child. Where parents did not see themselves as having a choice, this was sometimes because of limited service provision. Responsibility for the procedures could be the domain of just one parent, or it could be shared between two.

Carrying out the procedures was a difficult experience for most parents because of the distress the procedures caused for the child. Strategies, such as disconnecting and masking emotions, were used to manage how they felt when carrying out the procedures. The extent to which this emotional burden was a significant problem, or whether the burden lessened over time, varied between parents. In most cases, there was a sense that whilst it was something they did not like doing, and sometimes struggled with in the moment of carrying out the procedure, parents came to accept the responsibility for the procedure and, over time, it was normalised within wider care and nursing responsibilities. For a minority, however, carrying out the procedures presented an ongoing burden or concern; an absence of support, worries about how the child viewed the parent, and a perceived lack of choice in carrying out the procedures appear to be associated with this experience.

In taking on these procedures, parents had concerns about how to manage both verbal and physical resistance from their child and their child's distress. This went on to become a central part of their experience, yet not all felt confident about managing their child's distress and resistance. Parents used various techniques to make the procedures less distressing for their child, but the extent to which these were felt to be successful varied, and some wanted advice on this issue. Age and the cognitive ability of the child were linked with the perceived success of some strategies parents used to minimise their child's distress. Managing physical resistance was also a concern for parents, particularly when

carrying out the procedures was seen to be a two person job and there was no second parent or family member to assist.

Siblings' presence during procedures (and their reactions) could also be concerns. There were, however, contrasting views about what was acceptable. For those who were single parents or had no one to help them during the procedures, sibling presence was a necessity rather than a choice.

Finally, some parents, particularly those responsible for 'higher risk' procedures, reported concerns regarding the implications of doing procedures incorrectly.

When parents are responsible for administering these procedures, what is the perceived impact of this on the parent-child relationship, parental and child wellbeing, and the family?

As noted above, this responsibility presented a degree of emotional burden for parents, though in most cases, it did not appear to culminate in a significant ongoing problem. Similarly, whilst parents reported friction between them and their child during the procedures, there was no evidence that it had adversely affected their relationship. For a minority, however, there were concerns about how the child viewed them because of their role in the procedures. Where most prominent, this was linked to a lack of support with the role, a perceived absence of choice in taking on the procedures, and concerns about being able to manage the child's distress. There was no evidence, however, that parents felt their involvement in the procedures had adversely affected other children in the house or spousal relationships.

How do parents want to be supported with this responsibility, both when being trained and prepared to undertake such procedures, and in the longer-term?

The extent, nature and perceived quality of training when first taking on the procedure varied, but there was a clear message about what parents would value when being prepared to carry out these procedures. Good quality training allowed the parent time to practice and grow in confidence, was continually updated or 'refreshed' to check competency (with intermittent observation and supervision), provided sufficient information to the parent about the procedures, addressed anxieties and provided reassurance, included advice about ways to manage the child's distress and resistance, and included the provision of the contact details of available nurses to call for advice and reassurance if needed. Some parents had access to ward and community nurses for advice and reassurance following training, whilst others did not.

A range of needs were also identified for longer-term support (that is, after initial training is complete and parents are carrying out the procedures at home):

- Addressing the emotional side of the caring role, particularly involvement in procedures which cause a child distress.
- Recognition by healthcare staff of parents' contribution to the care of their child and the 'extra-ordinary' responsibilities they assumed.
- Access to peer support groups to share experiences.
- Assistance with the procedures (e.g. managing physical resistance).
- Having nurses undertake the procedures occasionally to alleviate the burden from parents.
- Accessible information about the procedures, such as what to do in times of uncertainty.

Implications of the research and recommendations for practice

In this section, we discuss the key implications arising from the findings of this study. In doing so we also draw upon a discussion that took place as part of a consultation workshop with parents, nurses, psychologists, play therapists and a WellChild representative regarding the findings, held in the final month of the project.

Meeting parents' support needs

At the core of our findings is the evidence that when parents administer nursing and healthcare procedures that cause their child distress, they do not *just* have to contend with its technical and clinical delivery (though it is important to note here that parents did express concerns about the ongoing monitoring of their competency in the procedures they were responsible for). There are additional issues they may have to manage: their child's distress and resistance, their own emotional response and the presence and reactions of siblings. These can represent significant challenges to parents, especially in the early days of having responsibility for a procedure and, for some parents, in the longer-term too. Despite the national stance to deliver healthcare closer to home, these issues and the associated training and support needs are not referred to in current policy and associated guidance.

The most prominent of these needs concerns having effective and appropriate skills or strategies to prevent or manage their child's distress. In our sample, some had received support of this nature, others had not. This raises questions about the best ways of up-skilling and supporting parents on this issue: what advice could and should be given, and by which professionals? Currently, there is guidance available for health staff for managing child distress during painful procedures that they carry out[13], but no equivalent for parents. Importantly, the extent to which the child was observed to find a procedure distressing was strongly linked to parents' accounts of their own emotional discomfort and sense of conflict between their role as parent and 'nurse'. Furthermore, it also appears to be associated with the degree to which parents successfully adapted to assuming responsibility for such procedures. For some parents the need to adequately manage their child's distress

may only be present during the early days of taking on responsibility for the procedure, for others it may be a more enduring support need.

A second, and linked, need arises from parents' accounts that they found witnessing their child's distress emotionally challenging. Some parents explicitly noted that they would have welcomed recognition from staff of the emotional aspect of this role – both during initial training in the procedure and on an ongoing basis. Other parents were identified as a further potential source of emotional support.

A third area of support concerned parents' sense of competence with the procedure. Some parents specifically noted they would have valued ongoing reassurance, supervision/monitoring and/or (re)training in the procedure.

The final area of support concerns the provision of practical support, either in routinely assisting parents (this could particularly be an issue for lone parents and/or those where the child was very resistant to a procedure being carried out) or occasionally the nursing team carrying out the procedures in order to alleviate the care burden on parents.

Some of these supports are clearly the domain of the nursing team. However, for others, there are questions about the best ways to offer this, and who is best placed to do so. It was noted in the consultation event that play therapy and paediatric psychology could play a role in up-skilling parents to manage distress or resistance and/or addressing parents' emotional support needs. However, whilst readily available in oncology and diabetes, these professionals are not routinely incorporated into teams caring for children with complex health needs and their families. Specialist input to meet these particular support needs may represent a small additional cost to the NHS, yet there were other forms of important support identified that are essentially cost neutral. Nurses recognising the responsibility parents have and providing reassurance, for example, are small actions that may potentially go a long way in supporting parents.

➔ Recommendations and considerations for practice (1)

Good training: is paced, not rushed, involves sufficient practice and gives parents enough time to become confident, allows them to talk through their anxieties and includes written information to refer to later. It also includes advice about managing distress and resistance, allows parents to take time out of training if it becomes too emotionally uncomfortable for them, and finishes with the contact details of nurses to call for help and advice.

➔ Recommendations and considerations for practice (2)

Parents want to **manage the distress their child experiences** when they carry out nursing and healthcare procedures at home. Some develop techniques to do this on their own whilst others want advice and help with this. This could be explored with parents during the training period. Play therapists may be a good source of advice.

➔ Recommendations and considerations for practice (3)

Parents value **recognition** (from health staff) of what they are doing, **emotional support**, and **reassurance** they are getting it right. Provision of emotional support may have implications for costs. However, the ability of nurses to provide recognition and reassurance may be one simple and immediate way of supporting parents.

Recognition of an invisible care environment

It is also important to consider the implications of the findings given the relative 'invisibility' (to NHS staff) of this particular care environment at the times when these procedures are being carried out. In addition to executing what may be a complex procedure, parents may also be managing the demands of their child's distress and/or resistance, their own emotional response and siblings' presence. These additional issues may not be immediately apparent to staff when they train parents in the procedures. There may, therefore, need to be a greater awareness of these issues; perhaps particularly for nurses who are ward, rather than community, based. Given that parents may not receive ongoing support or input once they have taken on responsibility for a procedure, it is not clear how a wider assessment of a parents' capacities to take on procedures, and on the need to provide ongoing support, can or does take place.

Furthermore, concerns about the child's safety were also raised by the parents we interviewed. The fact that these procedures take place in the home, sometimes with little ongoing oversight from nursing teams, raises questions about what happens if parents' fears are realised and they do get procedures 'wrong' (with consequences for harming the child) or their management of the procedure 'drifts' from the protocol they were trained in. Given the setting, it is clearly possible that events such as these may go unnoticed by healthcare staffs. Certainly, some of the parents we interviewed expressed a need for reassurance in the way they were executing or managing procedures and/or for retraining. Professionals attending the project's consultation workshop suggested there may be value

in incorporating retraining into any subsequent hospital discharges. This would provide an opportunity for parents to address concerns and refresh their skills if desired.

➔ Recommendations and considerations for practice (4)

Carrying out procedures in the hospital environment is different to doing them at home. There may only be one parent present and thus **no one else to assist** if a second pair of hands is needed for restraint. There may be **young siblings present** whilst procedures are being carried out. Thus, any advice to parents about the best ways to manage procedures their child finds distressing should explore and take into account these individual, and **potentially 'hidden', circumstances**.

➔ Recommendations and considerations for practice (5)

When parents carry out these procedures at home on their own, they can have concerns about the **safety** of what they are doing, and anxieties about **getting it wrong**. Parents believed this could be eased by having access to a nurse to call for **advice and reassurance**, or having a nurse to visit occasionally to **refresh training and/or observe** and check the parent is confident and comfortable with the procedure

The lack of choice over assuming responsibility for a distressing procedure

Finally, the theme of choice intersected different aspects of parents' experiences. Some felt they did not have a choice in carrying out the procedures, whilst others did. What an absence of choice means for this particular group of parents in the longer term is unknown, but evidence from other groups of unpaid carers suggests that an absence of choice in the caring role is linked to emotional stress and perceived ill health[33]. The absence of choice in taking on these procedures because of perceived limited local services in a few cases also raises questions about whether there is adequate nursing provision to support the delivery of care closer to home. Inconsistent provision of supported children's care closer to home has been demonstrated elsewhere[34], and the possibility of an absence of choice highlighted here may be an implication of this 'patchiness'.

Further research

Part of the purpose of this research was to lay the groundwork for future research on this topic. In completing this study, we have identified three key issues which should be further investigated.

1. Developing and evaluating interventions to upskill parents on preventing and/or managing their child's distress and resistance.
2. Developing and evaluating interventions to support the ongoing competency of parents in delivering procedures.
3. Further investigation of issues of patient safety and management of 'unsafe events'.

Conclusions

As stated in the proposal for this project, the objective of this research was to '*conduct an exploratory, qualitative study to build a preliminary understanding of these issues*' [pertaining to parents' experiences of carrying out nursing and healthcare procedures that cause the child distress]. We have achieved this objective and generated evidence highlighting the additional issues and challenges that parents faced alongside the technical delivery of the procedure, what support is valued and needed, and the perceived consequences of having this responsibility. In doing this, we have highlighted a number of implications for how parents could be supported with this responsibility. Finally, we suggest three key issues which warrant further research.

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Appendices

1. Recruitment advertisement
2. Information leaflet
3. Registration of interest form (text)
4. Consent forms
 - a. Face to face interviews
 - b. Telephone interviews
5. Topic Guides
 - a. Parents undertaking the procedures
 - b. Spouses/partners who have no involvement
 - c. Spouses/partners who have some involvement

Appendix 1: Recruitment advertisement

Understanding Parents' Experiences of Administering Painful and Invasive Procedures: The PEAPIP project

Are you are a parent caring for a child with a long-term or complex condition? Are you responsible for carrying out nursing or healthcare procedures that you think your child finds painful and/or invasive? Is your child aged 10 years or less? If so, you might be interested in being involved in the PEAPIP project, which WellChild is funding.

The PEAPIP project wants to find out about parents' experiences of being responsible for carrying out nursing or healthcare procedures that you think your child finds painful and/or invasive. This is important research, which will help health professionals to understand how to better support parents in this situation.

Taking part involves an interview with you about your experiences of this. [Click here to find out more.](#)

Interested in taking part? Let us know by completing this online form – it will take no longer than five minutes. Once we've received your response, Gemma will be in touch to answer any questions, and make arrangements for an interview.

Alternatively, contact Gemma Spiers on 01904 321984, or at gemma.spiers@york.ac.uk

Appendix 2: Information leaflet



Parents' Experiences of Administering Painful and/or Invasive Procedures

- ➔ The **PEAPIP** project is about parents who are currently undertaking nursing or healthcare procedures they think their child finds painful and/or invasive, or have done so within the past three months.
- ➔ These procedures may **include, but are not limited to**: anal irrigation, giving injections, passing a naso-gastric tube, passing a naso-pharyngeal airway, administering suppositories, suctioning, tracheostomy care, catheterisation, or changing skin dressings.
- ➔ The purpose of this research is to understand parents' experiences of being responsible for carrying out these sorts of procedures, including the impact on parents, children and families, and how families can be better supported.
- ➔ The findings from this research will help health professionals to understand how to better prepare and support parents who have this responsibility.
- ➔ A major part of the research involves interviews with parents who are responsible for carrying out these procedures.
- ➔ The **PEAPIP** project is funded by WellChild, and is being carried out by a small team of researchers based at the University of York.
- ➔ If you are a parent responsible for carrying out nursing or healthcare procedures that you think your child finds painful and/or invasive, AND your child is aged ten years or less, we'd like to invite you to take part in an interview for this research.
- ➔ To say 'thank you' for taking part in the **PEAPIP** project, parents will receive £20.
- ➔ To find out more about this research and taking part, please scroll down to the next two pages.

Taking part in the PEAPIP project

Taking part involves an interview with one of the researchers. You can choose to have a researcher visit you, or to be interviewed over the phone. We find it helpful to audio-record research interviews; however, this is your choice. The interview will last around an hour, but some parents may choose to speak with us for longer.

We would like to ask you about: your experiences of undertaking the procedure, being trained to do the procedure, managing your child's reactions to the procedures, how you think undertaking these procedures affects you, your child and your family, and any support needs arising from this. You can choose not to answer questions, and you can end the interview at any time – you don't have to give a reason. If you would like to withdraw from the research after the interview, please let us know before August 2015.

After the interview, we will also ask if there is someone else in your family (e.g. your partner) who might also want to be interviewed for the project.

Making sure the PEAPIP project can make a difference

During the project, we will be blogging and tweeting about the research as it happens so that we can make as many people as possible aware of it, including parents and healthcare staff. We will not blog or tweet about individual parents taking part in the research. When we have finished the project, there will be a report about the findings as well as downloadable resources. We will send you details about how to access these. We will also go to practitioner conferences and workshops to tell healthcare staff about what we have found.

Interested in taking part in the PEAPIP project? Want to find out more?

Please complete the online Project Response Form by clicking [here](#) (or type bit.ly/peapips into your browser). The form asks for your contact details and some basic information about you and your child. Completing this form does not commit you to taking part in the study. Once we've received the form Gemma will get in touch to discuss taking part and, if you are happy to do so, make arrangements for an interview.

You can also contact Gemma directly on 01904 321984, or email: gemma.spiers@york.ac.uk.

Please note, if lots of parents are interested in taking part in the PEAPIP project, we may not be able to interview everyone. We will let you know as soon as possible once we've received your Project Response Form and/or spoken to you.

Keeping information and data safe

We will not tell anyone that you are taking part in the PEAPIP project. We will take great care to make sure no one who took part in the research can be identified in any publications resulting from this research.

All information you give us will be stored securely and will only be seen/read by members of the research team. Once we have finished using the information we have collected during the study we will take great care to dispose of it securely.

In very rare circumstances, researchers find they need to tell someone else about what they have heard during an interview. This only happens if an interviewee says something which makes the researcher think that the individual, or someone else, is at risk of serious harm. In these situations, wherever possible, the interviewee is informed about any actions taken.

Thank you for your interest in the PEAPIP project.



PEAPIP Project, Social Policy Research Unit, University of York, Heslington, York, YO10 5DD

If you would like to discuss any concerns about this project with an independent person, you can contact the SPSW departmental ethics committee at the following address: DEPARTMENT OF SOCIAL POLICY AND SOCIAL WORK ETHICS COMMITTEE, Alcuin B Block, Heslington, York, YO10 5DD; Telephone (01904) 321480; Email: atholynne.lonsdale@york.ac.uk



The Project Team: Gemma, Bryony and Sue

Appendix 3: Registration of interest form

NB. The following is the text of the response form. As the form was hosted online it is not possible to include it as it originally 'looked' here.

Thank you for your interest in taking part in the PEAPIP project.

Please use this form to give us your contact details and tell us a little bit about you and your child. All information you give will be treated in total confidence. The form will take less than five minutes to complete.

(Please note: this form should be completed by the parent responsible for carrying out the nursing or healthcare procedure(s) for their child)

Please click the next button to continue.

About you and your family

Are you the...?

Mother

Father

Other (please specify)

Are you...?

A lone parent

Married/living with a partner

Other (please specify)

About your child

The PEAPIP project is about parents who are responsible for carrying out nursing or healthcare procedures they think their child finds painful and/or invasive. This section is about the child for whom you carry out these procedures.

If you carry out these procedures for more than one child, please tell us about the child who you do these procedures for most often.

How old is your child?

Years

Months

Is your child a:

Boy

Girl

Please use the space below to tell us about your child's health condition or diagnosis:

Has your child had this condition from birth?

Yes

No → Approximately how long has your child had this condition?

Compared to other children their age, does your child have difficulties with learning and/or communication?

Yes - a lot
Yes - a little
No

About your nursing or healthcare responsibilities

We have listed below some procedures that can be painful and/or invasive.

Please use the options below to tell us the procedures you carry out for your child, and the procedures you do not. You might carry out other procedures that you think your child finds painful and/or invasive, which are not listed here. Please tell us about these too, using the 'other' options.

Injecting or other needle procedures
Passing a naso-gastric (NG) tube
Inserting a naso-pharyngeal airway (NPA)
Anal irrigation
Removal or changing of dressings
Tracheostomy care
Catheterisation
Suctioning
Other 1 (please describe)
Other 2 (please describe)
Other 3 (please describe)

Does anyone in your family help you with, or share responsibility for, doing this procedure(s)?

Yes - please tell us who this is (e.g. partner)
No

Which of the following aspects do you find difficult about being responsible for this procedure(s) (please select all that apply):

Getting equipment and supplies
How I feel when I am carrying out the procedure(s)
The practical aspects of doing the procedure(s)
How my child reacts when I carry out the procedure(s)
Not feeling supported enough
None of these
Other (please tell us):

Please rate your agreement or disagreement with the following statement:

At the moment, I am happy to have responsibility for this procedure(s)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

Getting in touch

Finally, please tell us your name and provide your contact details so that we can get in touch with you about the research:

Name
Landline Telephone Number
Mobile number
Address line 1
Address line 2
Address line 3
Post code
Email

What is your preferred method of contact?

What are the best times/days to contact you?

Appendix 4. Consent form



Consent form (Face to face interviews)

Please read the following statements, tick the appropriate box next to each statement, and then print and sign your name in the box below.

Have you understood the information given to you about this research?

☐ Yes ☐ No

Do you understand that your participation is voluntary, and that you can withdraw without giving a reason?

☐ Yes ☐ No

Do you understand that your participation in the research is confidential, and that the only exception to this is if you tell the researcher something that makes them think that you, or someone close to you, is at risk of serious harm?

☐ Yes ☐ No

Do you agree to take part in this research?

☐ Yes ☐ No

Do you agree to the following interview being audio recorded?

☐ Yes ☐ No

Participant's name:	
Participant's signature:	
Researcher's name:	
Researcher's signature:	
Date:	



Consent form (Telephone interviews)

The following to be read aloud by the researcher and the participant's answers audio recorded, prior to interview.

- Have you understood the information given to you about this research?
- Do you understand that your participation is voluntary, and that you can withdraw without giving a reason?
- Do you understand that your participation in the research is confidential, and that the only exception to this is if you tell the researcher something that makes them think that you, or someone close to you, is at risk of serious harm?
- Do you agree to take part in this research?
- Do you agree to the following interview being audio recorded?

Participant's name	
Date of audio recorded consent	

Researcher's name	
Researchers' signature	
Date	

Appendix 5. Topic Guides

PEAPIP



Topic guide (Parents undertaking the procedure)

Objective

To understand parents' experiences of administering painful and/or invasive procedures as part of caring for a child with a long-term or complex condition at home, including how they think it affects them, their child and their family, and how they want to be supported.

Introduction & consent

- Introduce self, organisation
- About the project
- What I will ask about
- Length of interview
- Voluntary, skipping questions, breaking and stopping
- Use of information
 - Confidentiality
 - Limits to confidentiality
 - Anonymisation
 - How findings will be reported
- Thank you payment
- Ask if any questions

Ensure consent form signed (F/F) or recorded (telephone)

***** TURN ON RECORDER *****

1. Background and history (BRIEF)

Aim: To understand any relevant details of participant's circumstances and background, and background of child's condition and care

- Participant demographic details – age, main daytime occupation
- Family composition
 - Immediate family in household, number of children, marital status
- Brief history of child's condition
- Care procedure(s) undertaken
 - Prompt those listed in response form, and check if any others (e.g. previously)
- (Where applicable) distribution of responsibility for undertaking care procedure(s) between parents/other family member.
- Before parent had taken on responsibility for procedures, experience of similar care

2. Preparing and training for undertaking the procedure(s)

Aim: to explore parents' experience of being prepared and trained for undertaking the procedure(s)

- Prior to parent taking on this responsibility, who did the procedure(s)
 - Hospital nurses/staff, Community nurses/staff
 - How did child react, how was this managed
 - Positive/negative experience
 - Parent
 - Child
- When and why was responsibility transferred to parent
- Experience of being prepared/trained in the procedure(s)

- What happened, when, where, who did the training
 - Training in safe restraint?
- Advice given by professionals on dealing with child responses
- Views, feelings and expectations about being trained in the procedure(s)
 - Choice, concerns, confidence in self
- Views about the support received from practitioners during training/preparation

3. Experience of undertaking the procedure(s)

Aim: to explore parents' experience of undertaking the procedure(s), both at first, and later

- Early experiences of undertaking the procedure(s)
 - What was/is done, how often
 - How did it go, problems/difficulties
 - Child's responses/reaction
 - Immediately – distress, resistance
 - After and between procedures - behaviours
 - Why does parent feel child reacts that way
 - How did experience differ from expectations of it when being trained
- Later experiences of undertaking the procedure(s)
 - What is done, how often
 - How did it go, problems/difficulties
 - Child's responses/reaction
 - Immediately - distress, resistance
 - After and between procedures - behaviours
 - Why does parent feel child reacts that way
 - Perceived change over time in child's reactions → explore why (e.g. compliance, strategies to help child, adjusting/getting used to it)
- Views/feelings about undertaking procedure(s) – 'then' and 'now'
 - Coping, mental cognitive strategies
 - Avoidance of procedures
 - If parent does not find undertaking the procedures difficult or problematic, see section 4b

- What would parent do when concerned, if it went wrong
 - Does parent have access to a nurse/other health professional for advice or 'supervision'? Is this something the parent would want?

CONTEXT – HOW THE PROCEDURE(S) COMPARES TO OTHER THINGS PARENT DOES AND CHILD EXPERIENCES

- Is this the most painful/invasive procedure the child experiences? Why? What else?
- Is this the most difficult thing you have had to do for your child? Why, why not?
- If multiple procedures are undertaken, which does parent most difficult and why? Which does child most difficult and why? Which does parent find easiest and why? Which does child find easiest and why?

4a. Managing reactions

Aim: to understand how parent responds to and manages the child's reactions to the procedure(s).
Refer to highlighted yellow above.

- Experience of, and views about, managing/ameliorating child's reactions to/distress arising from, the procedure(s)
 - What has been tried/what is done, why
 - How did this work
 - Use of restraint
- Experience of, and views about, responding to and managing own discomfort or distress arising from the procedure(s) (if applicable),
 - What has been tried/what is done, why
 - How did this work
 - Coping strategies

4b. Where parent does not find undertaking the procedures difficult

Aim: to understand what reasons may explain parents' positive experience/view that their involvement in procedures is not difficult for them.

- We know that some parents find it difficult to undertake procedures that their child finds painful/invasive, but it sounds like your experience has been more positive/you've experienced little difficulty.
 - Are there any reasons why this isn't particularly problematic for you?
 - Has this always been the case?

REFER TO RESPONSE FORM ANSWERS ON VIEWS ABOUT HAVING THIS RESPONSIBILITY IF REQUIRED

5. Perceived impact

Aim: to explore parents' views on if and how responsibility for the procedure(s) has affected them, their child and family

Parent undertaking the procedure

- If and how involvement in procedure(s) has affected them (refer to **Views/feelings** in section 3)

Child

- Views about if and how involvement in procedure(s) has affected relationship with child (Refer to earlier discussion about child's and parents' own responses)
 - Observations of any changes in parent-child relationship

Partner/spouse

- Views about if and how involvement in procedures has affected relationship with spouse/partner
 - Role of sharing/not sharing responsibility

Other children in house

- How do other children (if applicable) react to parent carrying out the procedure(s)
- Views about if and how involvement in procedures has affected relationship with other children

General family dynamics

- Views about if and how involvement in procedures has affected general family dynamics

6. Support needs

Aim: to understand the type of support parent has received, and what support they would like, for this responsibility

- Experience and views of support for their responsibility for carrying out procedure(s) received so far

- What support they have received
 - Public sector
 - Voluntary sector
 - Family/social
 - Peer support online
 - When support was received (e.g. training, later support)
 - What this support 'looks like'
 - Any support for managing child's reactions and own discomfort?
 - Any 'supervisory' support from nurses/other health professional?
 - Who initiated support
 - How parent finds this support
 - If this did not have this support, how might things be different in terms of their responsibility for carrying out procedure(s)
 - Examples of positive practice for being supported
- Views of outstanding and additional support needs
 - What would help address these

7. Closing

Aim: to get advice and suggestions for practitioners on how to support parents, children and families in this situation, and advice and suggestions for other parents in this situation

- Advice for practitioners
 - For supporting parent
 - For supporting child
 - For supporting other family members
 - Other advice
- Advice for other parents with similar responsibilities
- Anything else parent would like to say on the topic that was not covered

End of interview

- Thank parent for their time
- Give payment and get signed receipt
- Give assurance about confidentiality and anonymisation
- If applicable, ask about other person in family to interview

PEAPIP



Topic guide: PARTNERS/SPOUSES WHERE THEY HAVE NO INVOLVEMENT IN PROCEDURE(S)

Objective of the research

To understand parents' experiences of administering painful and/or invasive procedures as part of caring for a child with a long-term or complex condition at home, including how they think it affects them, their child and their family, and how they want to be supported.

We are also interested in speaking to other family members (e.g. a partner) of those we have interviewed. Where spouses and partners are not involved (in either carrying out the procedures or assisting the other parent), we want to understand their experiences of observing this and/or their views of how they think it might affect them, their partner, and their child.

Introduction & consent

- Introduce self, organisation
- About the project
- What I will ask about
- Length of interview
- Voluntary, skipping questions, breaking and stopping
- Use of information
 - Confidentiality
 - Limits to confidentiality
 - Anonymisation
 - How findings will be reported
- Thank you payment
- Ask if any questions

Ensure consent form signed (F/F) or recorded (telephone)

1. Background and history

Aim: To understand any relevant details of participant's circumstances and their role in caring for child

- Participant demographic details – age, day time occupation
- Participant's role in caring for child more generally
- Probe why no involvement in carrying out the procedures
 - E.g. not present when it happens because at work
 - Chose not to be involved → why?

2. Preparing and training for undertaking the procedure(s)

Aim: To understand participant's role when [other] parent was being trained in the procedure, and their own views about this

Did parent undergo any of the training? If so:

- Participant's role during training
 - What happened, when, where
- Views and expectations about being trained in the procedure
 - Choice about own participation, concerns
- Views about the support received from practitioners during training/preparation

If not, did they want to be trained? Why?

3. Experience/observations of other parent undertaking the procedure

Aim: To explore participants' experiences and views of [other] parent undertaking the procedure

- Is parent present (e.g. in the house/room) when other parent carries out the procedure?
 - If so,
 - What do they do?
 - Views about:
 - Observing what is done
 - Own responses/reaction
 - Child's responses/reaction
 - Immediately - distress, resistance
 - After and between procedures - behavioural disturbances
 - Perceived change over time in child's reactions
 - If not present when other parent carries out the procedure:
 - Is parent aware of what happens and how other parent and child find it?

4. Managing reactions/distress

Aim: To explore participants' experiences and views of managing child's, parents' and own reactions to procedure

IF PRESENT WHEN OTHER PARENT CARRIES OUT PROCEDURE

- Experience of, and views about, managing/ameliorating **child's** reactions to/distress arising from, the procedure
 - What has been tried/what is done, why
 - Any differences in how they and other parent manage child's reactions? Why?
 - How did this work
- Experience of, and views about, responding to and managing **own** discomfort or distress arising from the procedure (if applicable)
 - What has been tried/what is done, why
 - How did this work
- Experience of, and views about, responding to and managing **partner/other parent's** discomfort or distress arising from the procedure (if applicable),
 - What has been tried/what is done, why

- How did this work

IF NOT PRESENT WHEN OTHER PARENT CARRIES OUT PROCEDURE

- Any experience of managing **child's** reactions to procedure afterwards if and when present
- Any experience of responding to and managing **partner/other parent's** discomfort or distress arising from the procedure afterwards if and when present

5. Perceived impact

Aim: To explore participants' views on if and how the other parents' involvement in procedure(s) affects other parent, themselves, child and family

Explore perceived impact on:

IF PRESENT WHEN OTHER PARENT CARRIES OUT PROCEDURE

Themselves

- If and how observing other parent undertake procedure(s) has affected participant (refer to views/feelings)

WHETHER PRESENT OR NOT WHEN OTHER PARENT CARRIES OUT PROCEDURE

Child

- Views about if and how other parents' involvement in procedure(s) has affected their own relationship with child and/or other parents relationship with child
 - Observations of any changes in parent-child relationship

Partner/spouse

- Views about if and how other parents' involvement in procedures has affected them (other parent)
- Views about if and how other parents' involvement in procedures has affected spousal relationship

Other children in house

- How do other children (if applicable) react to parent carrying out the procedure(s)
- Views about if and how involvement in procedures has affected relationship with other children

General family dynamics

- Views about if and how other parents' involvement in procedures has affected general family dynamics

6. Support needs

Aim: To understand participants' experience and views of support received so far, and outstanding support needs

WHETHER OR NOT PRESENT

- Views of support received so far by other parent and self
- Views of outstanding and additional support needs of other parent and self
 - What would help address these

7. Closing

Aim: to get advice and suggestions for practitioners on how to support parents, children and families in this situation, and advice and suggestions for other parents in this situation

- Advice for practitioners
 - For supporting parent
 - For supporting child
 - For supporting other family members
 - Other advice
- Advice for parents
- Anything else parent would like to say on the topic that was not covered

End of interview

- **Thank parent for their time**
- **Give payment and get signed receipt**
- **Give assurance about confidentiality and anonymisation**

PEAPIP



Topic guide: PARTNERS/SPOUSES WHERE THEY HAVE SOME INVOLVEMENT IN PROCEDURE(S) – ASSISTING OTHER PARENT OR UNDERTAKING PROCEDURE

Objective of the research

To understand parents' experiences of administering painful and/or invasive procedures as part of caring for a child with a long-term or complex condition at home, including how they think it affects them, their child and their family, and how they want to be supported.

We are also interested in speaking to other family members (e.g. a partner) of those we have interviewed. Where spouses and partners are involved (in either carrying out the procedures or assisting the other parent), we want to understand their experiences of this and/or their views of how they think it might affect them, their partner, and their child.

Introduction & consent

- Introduce self, organisation
- About the project
- What I will ask about
- Length of interview
- Voluntary, skipping questions, breaking and stopping
- Use of information
 - Confidentiality
 - Limits to confidentiality
 - Anonymisation
 - How findings will be reported
- Thank you payment
- Ask if any questions

Ensure consent form signed (F/F) or recorded (telephone)

1. Background and history

Aim: To understand any relevant details of participant's circumstances and background, and background of child's condition and care

- Participant demographic details – age, main daytime occupation
- Before parent had taken on responsibility for/assisting with procedures, experience of similar care
- Distribution of responsibility for undertaking care procedure(s) between parents
 - Who does what?
 - Nature of spouse's involvement - Assisting other parent (e.g. distracting child, holding child)? Also carrying out procedures?
 - How was it decided who does what?
 - Has involvement changed or fluctuated over time?
 - Why?
 - Any role in occupying other children whilst other parent carries out procedures?

2. Preparing and training for undertaking the procedure(s)

Aim: to explore parents' experience of being prepared and trained for undertaking the procedure(s)

Was parent trained in the procedure(s)? If so:

- Experience of being prepared/trained in the procedure(s)
 - What happened, when, where
 - Who did the training – partner (ie. Other parent), professional?
 - Training in safe restraint?
 - Advice given by professionals on dealing with child responses
- Views, feelings and expectations about being trained in the procedure(s)/taking on responsibility?
 - Choice, concerns, confidence in self

- Views about the support received from practitioners during training/preparation

If not trained, did they want to be trained? Why?

If their role is more assisting parent and distracting child, were they given any advice about this? If so, what was it? If not, would they have wanted this?

3. Experience of undertaking the procedure(s)

Aim: to explore parents' experience of undertaking/assisting other parent with the procedure(s), both at first, and later use

- Early experiences of undertaking/assisting other parent with the procedure(s)
 - What was/is done, how often
 - How did it go, problems/difficulties
 - Child's responses/reaction
 - Immediately – distress, resistance
 - After and between procedures - behaviours
 - Why does parent feel child reacts that way
 - How did experience differ from expectations of it when being trained (if applicable)
- Later experiences of undertaking/assisting other parent with the procedure(s)
 - What is done, how often
 - How did it go, problems/difficulties
 - Child's responses/reaction
 - Immediately - distress, resistance
 - After and between procedures - behaviours
 - Why does parent feel child reacts that way
 - Perceived change over time in child's reactions → explore why (e.g. compliance, strategies to help child, adjusting/getting used to it)
- Views/feelings about undertaking/assisting other parent with the procedure(s) – 'then' and 'now'
 - Coping, mental cognitive strategies, Avoidance of procedures
 - Are they content with their role? Would they prefer to be more/less involved, or be involved in a different way?
 - If parent does not find undertaking/assisting other parent with the procedures difficult or problematic, see **section 4b**
- What would parent do when concerned, if it went wrong

CONTEXT – HOW THE PROCEDURE(S) COMPARES TO OTHER THINGS PARENT DOES AND CHILD EXPERIENCES

- Is this the most painful/invasive procedure the child experiences? Why? What else?
- Is this the most difficult thing you have had to do for your child? Why, why not?
- If multiple procedures are undertaken, which does parent most difficult and why? Which does child most difficult and why? Which does parent find easiest and why? Which does child find easiest and why?

4a. Managing reactions

Aim: to understand how parent responds to and manages the child's reactions to the procedure(s).

Refer to highlighted yellow above.

- Experience of, and views about, managing/ameliorating child's reactions to/distress arising from, the procedure(s)
 - What has been tried/what is done, why
 - Who does this (them and/or other parent)?
 - How did this work
 - Use of restraint
 - Any difference between parents in how they manage their child's reactions?
- Experience of, and views about, responding to and managing own discomfort or distress arising from the procedure(s) (if applicable),
 - What has been tried/what is done, why
 - How did this work
 - Coping strategies
 - Any difference between parents in how each manage their own discomfort?
 - Role in providing emotional support to other parent?

4b. Where parent does not find undertaking the procedures difficult

Aim: to understand what reasons may explain parents' positive experience/view that their involvement in procedures is not difficult for them.

- We know that some parents find it difficult to undertake procedures that their child finds painful/invasive, but it sounds like your experience has been more positive/you've experienced little difficulty.
 - Are there any reasons why this isn't particularly problematic for you?
 - Has this always been the case?

REFER TO RESPONSE FORM ANSWERS ON VIEWS ABOUT HAVING THIS RESPONSIBILITY IF REQUIRED

5. Perceived impact

Aim: to explore parents' views on if and how undertaking/assisting other parent with the procedure(s) has affected them, their child and family

Themselves

- If and how involvement in procedure(s) has affected them (refer to **Views/feelings** in section 3)

Child

- Views about if and how involvement in procedure(s) has affected relationship with child (Refer to earlier discussion about child's and parents' own responses)
 - Observations of any changes in parent-child relationship
 - Observations of any differences in own parent-child relationship, and other parents' parent-child relationship

Partner/spouse

- Views about if and how involvement in procedures has affected relationship with spouse/partner
 - Role of sharing responsibility
 - Tensions arising during/after procedure?
 - In terms of negotiating who does what regarding the procedures?
 - Providing emotional support to each other if they find the procedures difficult?

Other children in house

- How do other children (if applicable) react to parent carrying out the procedure(s)
- Views about if and how involvement in procedures has affected relationship with other children

General family dynamics

- Views about if and how involvement in procedures has affected general family dynamics

6. Support needs

Aim: to understand the type of support parent has received, and what support they would like, for undertaking/assisting other parent

- Experience and views of support) received so far for undertaking/assisting other parent with the procedure

- What support they have received
 - Public sector
 - Voluntary sector
 - Family/social
 - Peer support online
 - When support was received (e.g. training, later support)
 - What this support 'looks like'
 - Any support for managing child's reactions and own discomfort?
 - Any 'supervisory' support from nurses/other health professional?
 - Who initiated support
 - How parent finds this support
 - If this did not have this support, how might things be different in terms of their responsibility for carrying out procedure(s)
 - Examples of positive practice for being supported
- Views of outstanding and additional support needs
 - What would help address these
 - Does partner need more support in their role?

7. Closing

Aim: to get advice and suggestions for practitioners on how to support parents, children and families in this situation, and advice and suggestions for other parents in this situation

- Advice for practitioners
 - For supporting parent
 - For supporting child
 - For supporting other family members
 - Other advice
- Advice for other parents with similar responsibilities
- Anything else parent would like to say on the topic that was not covered

End of interview

- Thank parent for their time
- Give payment and get signed receipt
- Give assurance about confidentiality and anonymisation